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ABSTRACT

Ethical decisions are involved in life and death decisions for severely handicapped infants. Although it has become common practice for physicians not to treat severely handicapped infants, the ethical considerations involved in euthanasia are complex. A review of the literature reveals that concerns center around the quality of life of the defective infant and of the family, the sanctity of life, and protection of fundamental rights for the parents and child. It appears that many individuals who have a physical anomaly, such as a heart defect, are assisted in dying because they are mentally retarded. Because of these trends, members of professional organizations should be available to counsel and support families when a severely handicapped infant is born. In addition, financial assistance should be made available to parents to help allay the costs associated with prolonged medical care of a severely handicapped infant, and major organizations that advocate on behalf of the severely disabled should take decisive steps to ensure that the rights of severely handicapped infants are protected when life and death decisions are made. (SW)

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Euthanasia of Severely Handicapped Infants: Ethical Issues

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Euthanasia of Severely Handicapped Infants: Ethical Issues

Infanticide, throughout history, has been both accepted and rejected. In 318 A.D. Emperor Constatine ruled that humans could not be killed. Up until that time, almost all peoples (with the exception of Jews) practiced infanticide (Langer, 1974). However, the murder of children continued into modern times. As late as the nineteenth century, infanticide was a common event in England. Nazi Germany during World War II systematically engaged in a death-making campaign against those who were thought to be incompetent (Powell, Aiken and Smylie, 1982). Infanticide has been so frequently practiced, that anthropologists call it "the most widespread means of "birth" control in history (Begley, 1982, p. 78).

In contrast, in recent years, medical science has made tremendous advances in keeping severely handicapped infants alike. There has been an increase in the number of persons cured of cancer, organ transplants occur daily, and X-ray machines can perform surgical procedures. The average lifespan has been extended by thirty to forty years. Persons of all ages, who ordinarily would not have survived, live longer because of the progress made in medical technology. Hardman and Drew (1980, p. 165) wrote, "It is true that medicine has enhanced the quality of life for many, who without such intervention could not have continued productive lives. It is also true that this new technology has extended the lives of many hopeless and terminally ill patients".

Many of the advances in medical science have occurred in the neonatal nursery. Specialized care has significantly increased the survival of handicapped infants. Normand (1978, p. 285) has said that "A number of mothers will leave the hospital with their baby cradled in the arms of high-technology medicine". One study in Sheffield, England revealed that one-half of the first 850 afflicted infants who were referred for treatment in 1971 survived and that eighty percent of these were multiple handicapped. Sixty percent had an IQ of at least 80 while only fourteen percent had an IQ of below 60 (Normand, 1978).

A number of individuals have questioned whether severely multiple handicapped children should be allowed to survive infance. One unnamed researcher in England has concluded, "that it was not necessarily a kindness to offer treatment for all. Indeed, it was felt by some that the attaining of adolescence...was only a dubious tribute to medical achievement" (Normand, 1978, p. 288). In the United States, Duff and Campbell (1973) were among the first to openly acknowledge that conscious decisions are made that allow severely handicapped infants to die. They reported that approximately fourteen percent of the neonatal deaths that occurred involved withholding treatment. The Johns Hopkins case documented in the film "Who Should Survive" is another example of the withholding of treatment. These decisions are not limited to handicapped infants, however. The California Supreme Court refused to hear the case of Phillip Becker, a thirteen year old boy with Down's Syndrome who had a heart defect that could be corrected surgically. Although the State of California would have paid for the surgery, Phillip's parents argued against it on the grounds that it was too risky. In addition, they felt that because Phillip is mentally retarded, his life is not worth living. The U.S. Supreme reaffirmed this decision by refusing to hear the case.

The life and death decisions made by parents and physicians have wide ranging legal implications. Although it is common practice for physicians not to treat severely handicapped infants, neither case law nor statutory law has sanctioned euthanasia.

Under current laws, parents and physicians, when withholding care, are committing one or more crimes. These include murder, involuntary manslaughter, conspiracy and child abuse (Robertson, 1975, p. 217). However, Duff and Campbell (1973) believe that there are instances when violating the law is appropriate. Although the legal ramifications of euthanasia are far from settled, this paper will focus on the ethical issues of euthanasia.

Medical Ethics

The practice of withdrawal of treatment and allowing an individual to die is termed euthanasia.

Euthanasia can be voluntary or involuntary. Because infants are incapable of making conscious decisions, euthanasia in infants is termed involuntary. Euthanasia can be carried out through active or passive means. By withholding treatment, and not directly engaging in a pro-death activity, euthanasia occurs in a passive manner. Rachels (1975) has argued that this is an artificial distinction because by withholding treatment the physician is actively assisting the patient to die.

Medical ethics make a critical distinction between active and passive euthanasia (Rachels, 1975,). The American Medical Association has endorsed a statement that is opposed to mercy killing or to intentional termination of life. However, simultaneously it supports the "cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent" (Rachels, 1975, p.78).

Arguments have been made that killing and allowing to die are the same in some circumstances (Kary, 1980). Bayles (1980) stresses that there is a difference between the two positions. He, citing the John Hopkins case argues that allowing a person to die may be worse than killing.

Complicating the issue of treatment of defective infants is the issue of abortion and the defective fetus. Fletcher (1979) has addressed this topic. Ramsay (cited in Fletcher) agrues that abortion leads to infanticide. On the other extreme, Joseph Fletcher (cited in Fletcher, 1979) states that there is no difference between abortion of defective fetuses and non-treatment of defective infants. Fletcher (1979) argues that there is a difference between selective abortion and withholding treatment from defective new borns.

Ethical Issues

The ethical considerations involved in euthanasia are complex. A review of the literature revealed that concerns center around the quality of life of the defective infant and of the family, the sanctity of life, and protection of fundamental rights for the parents and child.

Quality of Life

It has been argued that the quality of life for severely and profoundly handicapped infants is poor. Some infants may be so profoundly impaired that they are not aware of themselves or of others around them. An infant who is blind, deaf, and has severe brain damage is unable to profit from or contribute to society. The court in the Karen Ann Quinlan case supported this argument and held that the quality of life for severely impaired individuals was not good.

Smith (1981) states that it is possible to let infants die, if it is in the best interests of the child. If the child has no possibility for happiness or excellence, then it may be better for the child to die.

Duff and Campbell (1973) and Brandt (1978) have written that there are mitigating reasons for considering euthanasia. Severely handicapped infants can drain a family physically, emotionally, and economically. Duff and Campbell (1973) reported that some families "thought there were limits to what they could bear or be expected to bear" (p. 97). Thus, the quality of life for the family members was the overriding concern.

In addition, Duff and Campbell (1976) argue that the use of medical technology can dehumanize patients and increase suffering. They felt that severely handicapped persons should be spared the indignities of this technology. Consequently, Duff and Campbell (1976) strongly state that both active and passive euthanasia should be allowed when treating defective newborns.

Fost (1981) argues against euthanasia. He feels that emotional, economic, and social reasons are not valid reasons for considering euthanasia.

Fletcher (1979) links the controversy over abortion with the case that is given to severely handicapped infants. He argues that if society is complacent over abortion, then the care that is given to severely handicapped infants may not be adequate.

In several cases, the courts have decided against euthanasia. In Application of Ciceno, the court held that treatment must be given when it is available. In re Hudson, the court also held that medical treatment be provided.

One concern of opponents of euthanasia, is the loss of self-esteen by those who practice euthanasia (Fletcher, 1975). In addition, Fletcher believes that in a society that supports euthanasia, mistrust can occur between mother and child. If a new baby's life is terminated, with your parents' consent, because it was "sick" then another child in the family might ask what will happen when the child is ill.

Sanctity of Life

A central issue in the involuntary euthanasia controversy is whether the lives of defective infants are worth less than the lives of other individuals. In a nationwide survey of pediatricians and pediatric surgeons (Shaw, 1977) found that an average of eighty-two percent (82%) of the physicians responding said they did not believe that the life of "each and every newborn infant" (p. 589) should be saved.

Kluge (1980), in a discussion of the criteria for brain death, writes that although an individual's brain may have ceased to function, the person may be alive according to the traditional criteria of presence of heart beat and respiration. Kluge argues that this distination discrepancy allows for the distinction between a human being and a person. One is a reflection of biological entity that is a member of the species homo sapiens (p. 252). A person "possesses the present functional capability for conscious awareness, or any human being whose cerebrum is structurally sufficiently like that of a normal adult human being..." (p. 252). Kluge (1978), concluded that many severely handicapped infants are not inherently human, and thus, may be candidates for euthanasia.

Walmsley (1978) and Robertson (1975), have argued that any infant is conceived a human and has the right to exist. Harris (1981), has written that unless it can clearly be shown that it is in the patient's own best interest to die, then treatment cannot be withheld. He questions whether the lives of defective infants are somehow less important than lives of other human beings. Even though infants and their families may undergo inconvenience, pain, anguish, and medical cost, infants are alive. To cause the death of these infants requires a high price on the part of parents and society. Robertson (1975) writes that because infants are human beings, they should have their lives prolonged.

Arguments in favor of non-treatment of newborns conflict with recent social and legal policies regarding right to treatment of the disabled. The Romeo (1982) decision favoring treatment of mentally retarded individuals is in direct conflict with this. If the lives of these individuals was not worth living, then it would be a waste of time, money and effort to improve their lives.

Protection of Rights

The rights of parents and other family members are a consideration when deciding whether to terminate the life of a severely handicapped infant. Duff and Campbell (1973) have argued that a severely handicapped infant may place great hardship on the family - more than it can endure.

Robertson (1975) wrote that parents should not be allowed to make life and death decisions for their severely handicapped infants.

Delvin (1981) takes the position that children are entitled to the same rights as all human beings and that the right to protection of life is a fundamental right.

In Maine Medical Center v. Houle, the court intervened when parents refused treatment fot their severely deformed child. The court held "that the defendents (parents) here in have no regret to withholding such treatment and that to do so constitutes neglect in the legal sense". The infant died before surgery could be performed.

The court reached an opposing position In re Phillip B. Although Phillip was a twelve year old with Down's Syndrome, the case is applicable to this discussion. The parental decision to withhold treatment was upheld by the court.

Decision Making

A central concern is how will the decision to continue or to withhold treatment is made. A number of solutions have been suggested. Sherlock (1979) has suggested that criteria be developed to justify the termination of lives.

Coburn (1980) argues four moral "principles" for use in deciding whether to terminate the life of a defective newborn:

1. It is impermissible to terminate the life of a defective newborn, actively or passively, when it is the case that (a) it cannot be concluded beyond any reasonable doubt that the infant would be better off dead, even if (b) it will be replaced and replaced by a child whose life prospects are better - even significantly better - and (c) it's death will confer significant net benefits on those most directly affected by it.

2. It is also impermissible to terminate the life of a defective newborn, either actively or passively, when (a) there is good reason for thinking that its life will not be worth living, even if (b) its death will confer significant net benefits on those most directly affected by it, provided (c) it will not undergo significant amounts of suffering prior to reaching "the age of reason".
3. It is, however, permissible to terminate the life of a defective newborn, either actively or passively, when there is good reason for thinking (a) that it will not survive the first several years of life, (b) that during those years its experiences will either be of no value to it or mainly negative, and (c) its death will confer significant net benefits to those most directly affected by it (p. 354).

Coburn realized that it may be difficult to actually live by these principles. But goes on to say that this is not sufficient reason for not using them.

Shaw (1978) has written that it is difficult to establish criteria and has suggested that euthanasia should be approached on a "case by case basis" with parents and physicians.

Sargeant (1978) argues that when making life and death decisions about defective infants, parents and physicians, by nature of their roles, are biased. Parents, at a time of grief are incapable of making a reasonable decision. Physicians, may be reluctant to admit their halplessness, and may be pushed beyond "reasonable" limits. Sargeant concludes that the courts are the appropriate area for making these decisions.

Heyman and Holtz (1975) believe the legal duty of physicians and parents is to provide treatment that is ordinary and reasonable. However, there are two

social principles which the court must weigh when considering what is ordinary and reasonable. The first is that when a child is born, it is a person. The second, which conflicts with this, is that an individual's life should not be sacrificed for another. The legal question with which the court is faced is defining what is "ordinary and reasonable" care in light of these legal and social considerations.

MacMillan (1978) offered a model for making life and death decisions. She suggested that the interests of the child and family should be noted, constant with current laws. However, flexibility and current moral values should be considered in making decisions.

In a review of the consent process, Hardman and Drew (1980) examined the elements of consent. The primary elements are: capacity, information, and voluntariness. In each of these areas, the authors see conflict for the parents. They believe like Sargeant (1978) that parents, in a time of stress, are unable to make rational decisions. With regard to "capacity", parents may not be able to engage in logical decision making. For the element of "information" parents may not have sufficient information to make a life or death decision. And, for "voluntariness," parent elements of coercion or constraint may influence the decision.

Several writers (Robertson, 1975; Macmillan, 1978) have suggested that the only way to solve the dilemma of who should make the decision is for the legislature to mandate the decision making process. Macmillan (1978) suggests the following steps be used in the process: 1) the physician determines that the infant's condition is medically infeasible; 2) the parents decide whether they would like to withhold treatment; 3) the court review the decision. Heyman and Soltz (1975)

do not see the likelihood of action by legislature. Hardman and Drew (1980) argue that it is not in the best interests of society for the legislature to enact laws with regard to euthanasia in infants.

Mental Retardation as a Factor

If a mental retardation were not a factor, would euthanasia be even considered? The decision made by parents and physicians to allow the child to die, may be based solely on the fact that the child is mentally retarded. When a mentally retarded child is born with a physical defect that is corrected surgically, the decision not to operate may be used to save the life of the child. Phillip Becker's parents argued against life-saving surgery on the grounds that his life was not worth living. The presence of the heart deffect, allowed a decision to be made in favor of an early death for this child. If he had not been mentally retarded, the question of whether to treat him would not have arisen.

Smith (1981) found that infants who have Down's Syndrome may be allowed to die although any physical defect they have may be treatable.

In a recent Indiana court decision, two cases filed on behalf of "Infant Doe" to provide medical treatment to the Down's Syndrome infant, were dismissed. The parents requested that medical treatment be withheld from their son. The court agreed with them. Reacting to this, the U.S. Health and Human Services Department cited the Rehabilitation Act of 1973 and warned hospitals who receive Federal funds under Medicaid and Medicare not to discriminate solely on the basis of handicap.

Wolfensberger (1980) has equated euthanasia with "death-making" of handicapped persons. Wolfensberger is one of the few who has argued against euthanasia. He offered several suggestions including challenging the practice of euthanasia in the courts and engaging in civil disobedience.

Will (1980) has suggested that euthanasia is protected because, "People who are ignorant about retardation, or eager to believe the worst, often produce or sieze upon excessively pessimistic prognoses about retarded children's potentialities. These prognoses become self-fulfilling even fatal, when used to justify neglect". (p.112)

Conclusion

It is evident that euthanasia in infants is widespread (Duff and Campbell, 1973; Fletcher, 1978; Robertson 1975). Advances in medical science have led to the prolongation of life for many severely handicapped infants.

Sherlock (1979) summarized the arguments of those advocating euthanasia. They include: 1) infants' lives lack dignity; 2) they are a burden on themselves and society; 3) the suffering of defective infants is too much for the infants to bear; and 4) infants are less than human and therefore not entitled to rights.

It appears that many individuals are assisted in dying because they are mentally retarded. When these individuals have a physical anomaly, such as an intestinal obstruction or heart defect, it becomes convenient to end their lives. Wolfensberger (1980) has been one of the few opponents of euthanasia and has urged others to join him in opposing this "new wave".

Professionals have been urged to inform themselves about the issues involved in euthanasia (Powell, Aiken and Smylie, 1982). This paper attempts to go beyond this most necessary suggestion. The author would like to suggest several additional steps:

1. Members of professional organizations such as the Association for the Severely Handicapped, the Council for Exceptional Children, the American Association on Mental Deficiency and others be available to counsel and support families when a severely handicapped infant is born.

2. Financial assistance be made available to parents to help allay the costs associated with prolonged medical care of a severely handicapped infant.

3. Major organizations that advocate on behalf of severely handicapped persons take decisive steps to ensure that the rights of severely handicapped infants are protected when life and death decisions are made.

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